

Alternative Support Systems for LGBTQ+ Care Partners

Understanding Unique Challenges &
Evidence-Based Care Approaches

Northern Virginia Dementia Care Consortium (NVDCC)

Caregiver Conference

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www.insightmcc.org



Learning Objectives

01

Prevalence & Risk

Identify dementia prevalence and increased risk factors in LGBTQ+ older adults

02

Unique Challenges

Understand barriers faced by LGBTQ+ individuals with dementia and caregivers

03

Evidence-Based Care

Recognize proven interventions and support programs

04

Resources

Identify key organizations for LGBTQ+ dementia care

05

Cultural Competency

Apply inclusive care principles in practice

The Scope: How Many Are Affected?



455K

Current Cases

LGBTQ+ Americans living with dementia today

29%

Higher Risk

More likely to report memory loss than cisgender/heterosexual peers

20%

Transgender Prevalence

Compared to 12% in cisgender adults age 65+

1M+

By 2030

Projected LGBTQ+ older adults with dementia

Annual care costs projected at \$17 billion, highlighting urgent need for culturally competent services.



Why Higher Risk?

Lifetime Stress & Health Disparities

- *Higher rates of clinical depression and PTSD*
- *Increased social isolation and loneliness*
- *Minority stress from discrimination*
- *Higher cardiovascular disease, hypertension, stroke*
- *Substance use disparities*
- *Unemployment/poverty from workplace discrimination*

Historical Trauma

- *Lived when homosexuality was criminal (until 1967-1982)*
- *Classified as mental illness until 1973*
- *Survived AIDS crisis*
- *Experienced systemic discrimination*



The Double Stigma

LGBTQ+ individuals with dementia face compounding marginalization: stigma from sexual orientation/gender identity PLUS stigma from dementia diagnosis. This creates fear of disclosure in healthcare settings and re-closeting in care environments.

"At the hospital, in the surgery, with social services... people ask us who we are. And the pain in the gut feeling you get as each time you make the choice about delivering the fundamental information about yourself."



Identity Disclosure: A Continuous Challenge



Never One-Time

Disclosure continuous in every new setting, not a single event

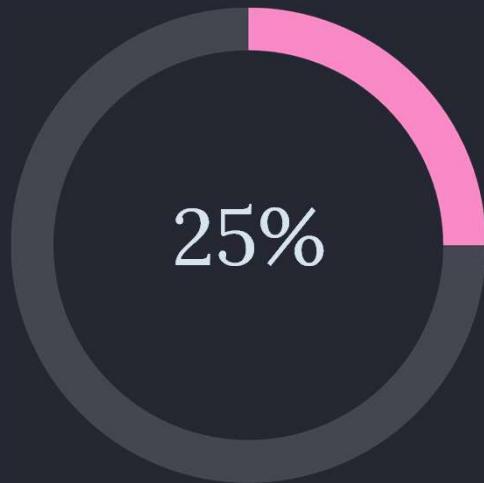
Dementia Impact

Undermines autonomy over disclosure decisions; may reveal previously hidden identity

Safety Concerns

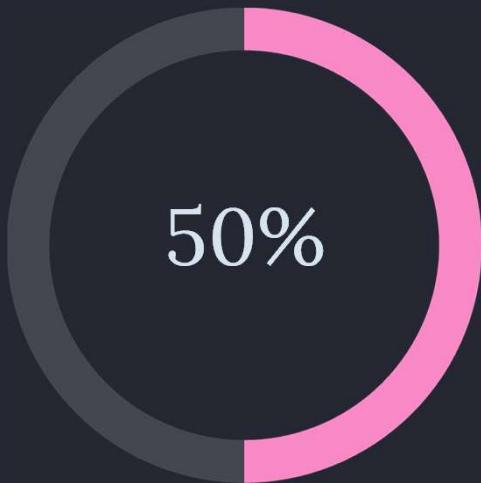
Fear discrimination will affect quality of care; worry about rejection

Family Structure: Different Support Systems



Gay/Bisexual Men

Have children



Lesbian/Bisexual Women

Have children



Heterosexual Adults

Have children

- ❑ **Chosen Families:** Close friends function as family. Partners and ex-partners serve as caregivers but may lack legal recognition. Chosen families often aging together with fewer intergenerational networks.

Healthcare Access: Significant Barriers

Fear & Avoidance

15% fear accessing healthcare outside LGBTQ+ community

13% denied care or received inferior care

Over 1/3 of transgender individuals experienced discrimination

Provider Gaps

Lack of culturally competent providers

Heteronormative assumptions in care

Limited LGBTQ+ training among dementia providers

Consequences

Many dementia cases likely undiagnosed/untreated

22% of transgender people postpone medical treatment

Caregiver Experiences: Five Key Themes



Caregiver Tension &
Isolation

*Small social networks, estrangement
from family*

Financial Stress & Security

*Lifetime discrimination creates
economic vulnerability*

Lack of Social Support

*Difficulty finding LGBTQ+-specific
groups*



Engineering Grief Support

Limited culturally appropriate resources

Past & Present Stigma

Ongoing discrimination during dementia care

Who Provides Care?

LGBTQ+ Caregiving Patterns

- *Primarily care for parents and familial relatives*
- *Transgender/gender diverse adults more likely to be caregivers*
- *1 in 5 LGBTQ+ people provide care vs. 1 in 6 non-LGBTQ+*
- *9% of all US caregivers are LGBTQ+ (3 million people)*

Unique Challenges

- *Care recipients often hold different political views*
- *Less family, coworker, neighbor support*
- *Partners excluded by biological family*

Aging with Pride: IDEA

Innovations in Dementia Empowerment and Action — First federally-funded study for LGBTQ+ dementia care, led by Dr. Karen Fredriksen-Goldsen at University of Washington.

Program Structure

Free 6-week intervention with dyad participation (person with dementia + care partner)

Key Components

9 one-hour coaching sessions focusing on problem-solving, communication, low-impact exercise

Compensation

\$125 for completing assessments. Built on proven RDAD model, tailored for LGBTQ+ needs

Access: ageIDEA.org | 1-888-655-6646



Why IDEA Works



Evidence-Based

Cognitive behavioral intervention proven effective, specifically addresses LGBTQ+ risk factors



Culturally Tailored

First intervention of its kind nationwide, designed for community needs



Comprehensive

Problem-solving, communication enhancement, physical activity, stress management



Support Groups: Critical but Hard to Find

"That saved me... the support group and nobody has any problem with my being a lesbian."

"I would love to have a lesbian support group... but I don't know of any way to start one."

Positive Impact

- *Reduces caregiver isolation*
- *Creates safe space for identity discussion*
- *Peer support from shared experiences*

Available Programs

- *Brighton & Hove LGBT Switchboard Dementia Project*
- *ALZConnected LGBTQ+ forum*
- *Opening Doors online support groups*



Cultural Competency Training

Training Programs

- *SAGECare organizational training*
- *Alzheimer's Foundation of America courses*
- *"Supporting the LGBTQIA+ Community in Dementia Care"*

Proven Impact

- *Increases positive attitudes, empathy, knowledge*
- *Improves provider preparedness*
- *Promotes organizational policy changes*
- *Reduces discrimination in care settings*

Creating Safer Spaces



Visual Cues

Rainbow flags, LGBTQ+ affirming posters, same-sex couple imagery in materials



Inclusive Forms

Gender-neutral language, inclusive intake forms with SOGI questions



Staff Visibility

Rainbow badges/lanyards, pronoun sharing, inclusive language modeling

Why It Works: Signals safety and acceptance, reduces anxiety about disclosure, communicates organizational values, encourages service utilization.

Legal Protections & Advance Planning



Gender Recognition Certificates

If needed for legal identity documentation



Healthcare Power of Attorney

Ensure partners can make medical decisions



Advance Directives

Specify LGBTQ+-inclusive care preferences



Legal Marriage Documentation

Partnership recognition and protections





SAGE: The Gold Standard Organization

Services & Advocacy for LGBTQ+ Elders – Founded 1978, oldest and largest LGBTQ+ aging organization

SAGECare

Cultural competency training for providers

SAGEServes

Direct services, care management, friendly visiting

National Resource Center

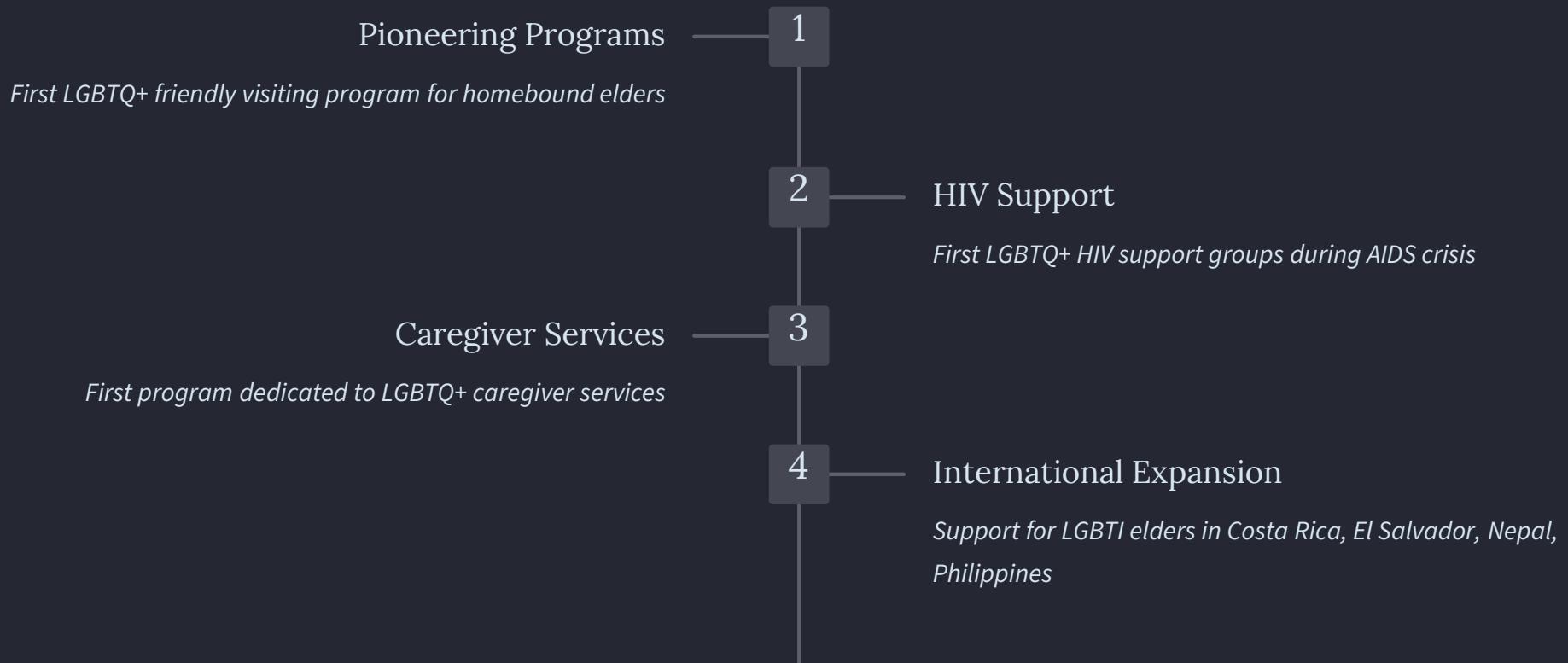
LGBTQ+ aging resources and research

SAGE Centers

Four NYC centers, programs in Florida

National LGBTQ+ Elder Hotline: 877-360-5428 | Website: sageusa.org

SAGE: Historic Achievements



Current Reach: Partner organizations throughout US and Puerto Rico, thousands of elders served annually.



Long-Term Care Equality Index

HRC Foundation & SAGE Partnership — Launched 2019

What It Does

- *Evaluates long-term care facilities on LGBTQ+ inclusion*
- *Provides roadmap for inclusive policies*
- *Offers free technical assistance*
- *Recognizes "Leader" and "High Performer" facilities*

2025 Results

- *274 communities across 33 states participating*
- *90% updated non-discrimination policies*
- *Memory care communities included*

Access: TheLEI.org

LEI: Benchmarking Criteria

Non-Discrimination Policies

LGBTQ+-inclusive for residents and employees

Staff Training

80%+ completion requirement on LGBTQ+ competency

Equal Visitation

Policies ensuring partner access and recognition

Inclusive Documentation

Forms and procedures respecting identity

Public Commitment

Visible demonstration of LGBTQ+ affirmation



Alzheimer's Association Partnership

National Resources

Issues Brief: LGBTQ+ and Dementia (with SAGE), comprehensive guides, caregiver concerns PDF

Online Community

ALZConnected LGBTQ+ forum – free online support community

ALZPride

Voices of the LGBTQ+ Community panel discussion series

Organizational Commitment

Health equity, early diagnosis access, quality care standards, diverse research perspectives

Leading Researchers



Dr. Karen Fredriksen-Goldsen

University of Washington. Director, Healthy Generations Hartford Center. Leading Aging with Pride: NHAS and IDEA studies. PBS Next Avenue Top 50 Influencers in Aging.



Professor Elizabeth Peel
Loughborough University, UK. "Over the Rainbow" project (2015). 21 research grants worth £2M, nearly 200 publications on LGBTQ+ dementia care.

Other Key Researchers

Dr. Jason Flatt

UC San Francisco — First large-scale dementia prevalence study in LGB adults. 7.4% prevalence in 3,718 sexual minority adults 60+

Dr. Claudio Di Lorito

University of Nottingham — Scoping review of LGBT caregiver support needs, international evidence synthesis

Dr. Jaclyn White

Brown University — Medicare recipients study, transgender dementia prevalence research (20% vs 12%)

What Works



Supporting Different Family Structures

Single LGBTQ+ Seniors

Challenges: *Small social networks, estrangement from biological families, chosen families aging together*

Interventions: *Peer support networks, friendly visiting programs (SAGE model), care management recognizing chosen families, virtual support options*

Partnered/Married Seniors

Challenges: *Partners excluded by biological families, lack of recognition as "legitimate" couples, legal/medical decision-making barriers*

Interventions: *Legal protections for partner decisions, couples-focused interventions (IDEA), equal visitation enforcement, explicit partner recognition*

Cultural Competency: Practical Steps

For Providers

Complete LGBTQ+ training, use gender-neutral language, include SOGI on intake forms, display visual affirmation, never assume family structure, ask preferred names/pronouns

For Organizations

Develop inclusive non-discrimination policies, participate in LEI, require staff training (80%+ goal), create LGBTQ+ advisory groups, partner with SAGE, update all materials



Addressing Historical Trauma

Understanding Context

Older adults lived when homosexuality was criminal, experienced conversion therapy, lost partners to AIDS crisis, faced institutionalization, police raids, violence, job loss, eviction

Care Implications

May re-closet when vulnerable, distrust authority figures, have trauma responses to medical settings. Need ongoing reassurance of safety and acceptance.



Essential Resources



Immediate Support

SAGE National LGBTQ+ Elder Hotline:
877-360-5428

Eldercare Locator: 800-677-1116

ALZConnected LGBTQ+ Forum:
alz.org



Information & Guides

SAGECare.org — Training and caregiver resources
"Facing the Future Together" guide
(SAGE & HRC)

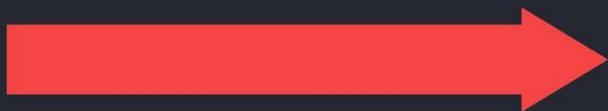
National Resource Center:
lgbtagingcenter.org



Research Participation

AgeIDEA.org — Join IDEA study
Call: 1-888-655-6646

Take Action Today



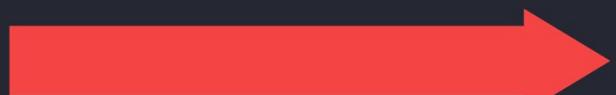
Caregivers

Connect with LGBTQ+-specific support groups, complete advance care planning with legal protections, find affirming providers using LEI directory, join research studies



Providers

Complete cultural competency training, add visual cues of affirmation, update intake forms with SOGI questions, audit policies for inclusion, use inclusive language



Advocates

Support LGBTQ+ aging organizations, advocate for inclusive policies, share resources, participate in awareness events, push for data collection in research



Together, We Can Create Change

LGBTQ+ elders with dementia deserve recognition, respect, and care tailored to their unique needs and experiences. With education, awareness, and intentional inclusion, we can ensure dignified, affirming care for all older adults.

Every small change in practice makes a difference. You have the power to create safer, more welcoming care environments starting today.



Key Resources: SAGE: 877-360-5428 | TheLEI.org | AgeIdea.org | sageusa.org

Questions & Answers

Open for discussion and questions from the audience.

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